

- Provision of easily accessible palliative care
- Access to support for patients and carers

These aims are delivered by care networks and assessed by prospective continuous audit of key outcome measures.

**Lung cancer in Scotland** has had poor and unchanging <sup>1</sup>outcomes ascribed to low and uneven access to optimal care<sup>2</sup>. The variable experience and suboptimal care provided for patients with lung cancer in Scotland was further highlighted during a national programme of standard setting and peer review organised by the Clinical Standards Board for Scotland.<sup>3</sup> During a period spanning 2000/1 every hospital providing lung cancer care was assessed by submitting a self report on defined number of service standards and subsequent external review which included patients and carers.

We describe the process of **reorganisation of lung cancer services** in Scotland over the last twelve years and its effects on outcomes for patients with lung cancer.

In 2001, Scotland launched a **comprehensive national cancer strategy**<sup>4</sup>, which radically changed the way that all cancer services are planned and delivered. The benefits of this reorganisation that are relevant to lung cancer include:

- formation of multidisciplinary disease specific networks serving a defined population area and working across organisational boundaries
- access to multi-disciplinary decision making
- establishment of prospective audit measuring and reporting comprehensive service performance against national standards based on evidence based guidelines (SIGN)

This national program of reform was supported by about \$500 million of additional targeted investment providing:

- improvements in diagnostic facilities particularly increased CT scanning capacity
- improved access to modern radiotherapy with replacement of old equipment and expansion of existing capacity and access to 3D conformal treatment
- improved access to new drugs through a national programme of review and regional implementation
- national PET programme
- cancer trials network that has led to 13% of all Scottish cancer patients participating in clinical trials.
- appointment of additional staff

Impact of these changes is seen in comparison of lung cancer patients cohorts within defined geographical area served by one cancer network ([www.scan.scot.nhs.uk](http://www.scan.scot.nhs.uk)) and participating in prospective audit with >90% capture and 98% accuracy.

#### Comparison of treatment intent and delivery

	1995, N=927	2002, N=971	2004, N=939	Chi squared
Any treatment	582 (63%)	605 (62%)	568 (60%)	P=0.85
Potentially curative	131 (14%)	229 (24%)	230 (25%)	P<0.001
Palliative	451 (49%)	376 (39%)	338 (35%)	
Surgery	95 (10.2%)	102 (10.5%)	91 (9.7%)	P=0.88
Radiotherapy	400 (43%)	433 (45%)	378 (40%)	P=0.55
Radical <sup>1</sup>	44 (4.7%)	146 (15%)	149 (16%)	P<0.001
Palliative	356 (38%)	296 (31%)	229 (24%)	
Chemotherapy	151 (16%)	196 (20%)	249 (27%)	249 (27%)

#### Survival comparison

	Median	1 year	2 year
1995 N=927	4.1(3.5-4.6)	23.4% (20.7-26.1)	11.4% (9.3-13.5)
2002N=971	5.1 (4.5-5.8)	28.9% (26.1-31.8)	14.8% (12.5-17.1)

Log rank p=0.0029,

In addition to the hard endpoints of treatment and survival these reforms have radically improved qualitative measures such as access to information, Clinical Nurse Specialists and symptom management.

One remaining question is why do 1 in 3 Scottish cancer patients still do not receive any anti-cancer therapy? It may be appropriate in elderly population with high levels of co-morbidity, but further prospective population based studies of the decision making process are required.

- 1 Fergusson RJ, Gregor A, Dodds R, et al Management of lung cancer in South East Scotland. *Thorax*, 1996.51(6):569-74
- 2 Gregor, A., Thomson, C.S, Brewster, D.H. et al Management and survival of patients with lung cancer in Scotland diagnosed in 1995. *Thorax*, 2001.56 (3):212-7
- 3 Clinical Standards Board for Scotland, [www.nhshealthquality.org](http://www.nhshealthquality.org)
- 4 Cancer in Scotland: action for change. Edinburgh: NHS Scotland [www.show.scot.nhs.uk/sehd/cancerinscotland](http://www.show.scot.nhs.uk/sehd/cancerinscotland)

**M20-03 Patients - Health Care Provider Communication, Thur, Sept 6, 10:30 - 12:00**

#### Decision-making of lung cancer patients and family

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Sometimes it is not easy to decide whether to treat or not in lung cancer patients (1). Among patients who died of lung cancer, significant proportions were found to have received chemotherapy up to the end-of-life and to have visited ERs. Palliative care and hospice referrals were not conducted well during the end-of-life period (2).

#### Palliative Chemotherapy:

Among patients who died of cancer, chemotherapy was used frequently in the last 3 months of life. The cancer's responsiveness to chemotherapy does not seem to influence whether dying patients receive chemotherapy at the end of life (3).

In our study, newly diagnosed chemo-naïve patients with advanced or recurrent NSCLC (n= 404) were evaluated. All patients were histologically or pathologically proven to be NSCLC, with performance status 0 to 2. All patients received platinum-based combination chemotherapy as the first-line treatment. The old age group was defined as patients with 65 years or more of age. The average number of total regimens (2.31 of old age vs. 2.81 of young age, respectively; p<0.001) and cycles (8.78 vs. 10.69, p=0.006) per head were significantly less in the old age group than in the young age group.

Multi-center study in Korea showed that 48.7 % of cancer patients in the last 6 months of life, 43.9% in the last 3 months, and 30.9% in the last month of life received chemotherapy in Korea. The frequency of chemotherapy use was lower for older patients (P for trend < 0.001). In those older than 65 years, there was no difference between women and men in the proportion that received chemotherapy. For patients < 65 years of age, however, a larger proportion of women than men received chemotherapy, and chemotherapy use was significantly less frequent for patients with refractory disease than for those with responsive disease. This difference, however, was lower for patients older than 65 years of age. Patients dying at a relatively small hospital without a hospice inpatient unit were significantly more likely to receive chemotherapy than patients at a larger, hospice-containing hospital, as were patients with

Medicaid relative to patients with national health Insurance. Despite the fact that most cancer patients are resistant to chemotherapy at the end of life, it was administered often to all age groups. The frequency of chemotherapy administration differed between men and women and between patients with and without chemo-responsive disease, and the differences varied with age.

#### End-of-Life Care:

Seoul National University Hospital data showed that median duration of chemotherapy was 6.02 months (mo) compared to 8.67 mo for median overall survival in cancer patients. The median period between last chemotherapy and death was 2.02 mo. Of the 298 patients, 50.3% received chemotherapy during the last two months of life. Furthermore, 17 patients (5.7%) died within 2 weeks after receiving chemotherapy. The proportion who visited an emergency room (ER) more than once during the last months of life was 33.6%, and the average number of ER visits after a diagnosis of cancer was 1.72. Only 9.1% of patients were referred to a hospice center and only 11.7% of patients agreed with written DNR.

In our study, 80 patients who admitted to ICU were evaluated. 51 (63.8%) patients died in ICU, and among 29 (36.3%) patients who survived their ICU stay, additional 13 (16.2%) died in general ward. Overall in-hospital mortality was 80% (64/80). Median survival from the time of intubation was 13 days for all patients (including survivors). Uncontrolled disease (disease progression after previous chemotherapy) and intubation more than three days after hospitalization were significantly associated with in-hospital deaths in uni-variate and multi-variate analysis. Old age (>60yrs), leukopenia, and performance status were not significant prognostic variables associated with in-hospital deaths. Mortality of cancer patients admitted to ICU for mechanical ventilation was very high. Patients with uncontrolled disease or long-term hospitalization prior to respiratory failure are not likely to benefit from intensive care.

#### Discrepancies among patients, family members, and physicians in terms of values:

Oh et al. showed difficulties in decision regarding the withholding of treatment from patients with terminal malignancies (4). 100% of the families and 87% of the patients has some knowledge of cancer, but only 69% of the families and 37% of the patients clearly understood the stage of cancer. The use of a new agent with only partial efficacy (ca. 15%) was accepted by 41% of the physicians and by 60% of the families. The concordance rate between physicians and family members, for the same patient was 42%. The rankings of the acceptance of treatment by physicians were, opioid analgesics (100%), antibiotics (91%), feeding tube (87%) and intravenous nutrition (78%). The rankings of the same items by family members were, opioid analgesics (92%), antibiotics (89%), intravenous nutrition (86%), feeding tube (75%). The concordance rate between physicians and families was lowest for ventilator application (39%) and CPR (47%).

#### Decision-making regarding participation in research and high-cost options:

Controversy surrounds the enrollment of terminally ill patients in research studies. Many people argue that because of the nature of their illness these individuals are vulnerable, ill informed, can be coerced. However, data suggested that terminally ill individuals are well informed about their cancer and well aware of most viable alternatives, from palliative care to hospice. Overall, it appears that concerns about the voluntariness and vulnerability of terminally ill patients are overstated and that their participation in clinical research at the end of life is

a well informed decision. (5) In addition, high-cost options in treatment of lung cancer are causing difficulties in decision.

#### Decision-making regarding palliative care:

Brundage et al. suggested that patients with advanced NSCLC should be offered more than one treatment option, and that a systematic process for educating patients and for eliciting their preferences is desirable (6). Values held on issues like therapeutic decision-making and the withholding of life-sustaining treatments in terminal cancer patients are discordant between physicians and family members. In order to resolve controversies on the role of physicians in end-of-life decisions, the values of physicians, patients and of family members should be considered in the final decision-making process.

In our study, 121 consecutive patients with advanced or terminal stage cancer were evaluated. The opinions of physicians, family member, and patients when family members permitted, using a questionnaire, were collected. About 30% of physicians and family members did not want to inform patients of the exact state of their diseases. When the opinions of patients, family members, and physicians differed concerning life-sustaining treatment of terminal cancer patients, 78.3% of physicians and 82.6% of patients believed that the final decision should be made by the patient. However, only 47.9% of family members believed so. Moreover, in real practice, the treatment decision was made by patients in only 33% of cases, whereas 33% of cases were directed by a physician and 28% by family members. For ideal decision-making, almost all favored an informed decision, whilst 69.3% of physicians, 64.8% of family members and 57.1% of patients favored a shared decision. More patients and family members than physicians regarded the role or responsibility of a physician as being of central importance.

Although informed shared decisions should be made concerning treatment-decisions in cancer patients, this is not usually reflected by practice. Medical decisions concerning the end-of-life care are very challenging to physicians, family members, and patients.

#### References

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- (2) Trends in the aggressiveness of cancer care near the end of life. *J Clin Oncol*. 2004;22:315-21.
- (3) Emanuel EJ, Young-Xu Y, Levinsky NG, Gazelle G, Saynina O, Ash AS. Chemotherapy use among Medicare beneficiaries at the end of life. *Ann Intern Med*. 2003;138:639-43.
- (4) Oh DY, Kim JE, Lee CH, Lim JS, Jung KH, Heo DS, Bang YJ, Kim NK. Discrepancies among patients, family members, and physicians in Korea in terms of values regarding the withholding of treatment from patients with terminal malignancies. *Cancer*. 2004 May 1;100(9):1961-6.
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